CLINICAL ETHICS

Are the GFRUP's recommendations for withholding or withdrawing treatments in critically ill children applicable? Results of a two-year survey

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Objective: To evaluate feasibility of the guidelines of the Groupe Francophone de Réanimation et Urgence Pédiatriques (French-speaking group of paediatric intensive and emergency care; GFRUP) for limitation of treatments in the paediatric intensive care unit (PICU).
Design: A 2-year prospective survey.
Setting: A 12-bed PICU at the Hôpital Jeanne de Flandre, Lille, France.
Patients: Were included when limitation of treatments was expected.
Results: Of 967 children admitted, 55 were included with a 2-day median delay. They were younger than others (24 *v* 60 months), had a higher paediatric risk of mortality (PRISM) score (14 *v* 4), and a higher paediatric overall performance category (POPC) score at admission (2 *v* 1); all $p<0.002$. 34 (50% of total deaths) children died. A limitation decision was made without meeting for 7 children who died: 6 received do-not-resuscitate orders (DNROs) and 1 received withholding decision. Decision-making meetings were organised for 31 children, and the following decisions were made: 12 DNROs (6 deaths and 6 survivals), 4 withholding (1 death and 3 survivals), with 14 withdrawing (14 deaths) and 1 continuing treatment (survival). After limitation, 21 (31% of total deaths) children died and 10 survived (POPC score 4). 13 procedures were interrupted because of death and 11 because of clinical improvement (POPC score 4). Parents' opinions were obtained after 4 family conferences (for a total of 110 min), 3 days after inclusion. The first meeting was planned for 6 days after inclusion and held on the 7th day after inclusion; 80% of parents were immediately informed of the decision, which was implemented after half a day.
Conclusions: GFRUPs procedure was applicable in most cases. The main difficulties were anticipating the correct date for the meeting and involving nurses in the procedure. Children for whom the procedure was interrupted because of clinical improvement and who survived in poor condition without a formal decision pointed out the need for medical criteria for questioning, which should systematically lead to a formal decision-making process.

In developed countries, ⩾70% of children die in hospital, mainly in paediatric intensive care units (PICUs).[1 2] Decisions on forgoing life-sustaining treatment are made for 30–40% of dying children.[3–5]

Although formal guidelines in the English language for withholding or withdrawing treatment in critically ill children have been available since the 1990s, recommendations in French were lacking until recently.[6–8] Because of this lack and because several studies have shown that French-speaking doctors in the intensive care units did not follow US guidelines,[9] the French-speaking group of the intensive care unit organised a workshop, including PICU nurses and doctors, parents of patients, palliative care specialists, philosophers and people who had conducted ethics research. This group worked from 1999 to 2000 and its conclusions were published in July 2002 as a book that was disseminated to all French PICUs.[10] Recently, French paediatric guidelines were derived directly from this text and validated by the ethics commission of the French Paediatric Society; the proposed procedure is summarised in box 1.[11] Contrary to English guidelines that regard parents as the most appropriate bearers of decisional authority, French guidelines are more doctor centred, recommending that parents choose their level of participation, without shifting the weight of responsibility for the decision on them.

The purpose of this study was to evaluate the feasibility of the procedure, to record related medical and paramedical time, and to point out ethical problems that could be implied by the procedure itself.

PATIENTS AND METHODS

This prospective study was carried out from September 2002 to August 2004 in a 12-bed French tertiary PICU at the Hôpital Jeanne de Flandre, Lille, France. All children consecutively admitted during this period were included. A specific paper file was completed during the PICU stay as soon as one member of the medical staff anticipated that an ethics discussion would be necessary. This population was defined as ''question-raising children''. Severity in patients was assessed by the paediatric risk of mortality (PRISM) score and performance at admission and discharge were assessed by the paediatric overall performance category (POPC) score.[12 13] Dates, durations, places and actors were recorded at each step of the decision-making process. The wishes of parents were classified into three categories: maximum supportive care, not expressed and limitation of treatments. The reactions of patients after the decision were classified into three categories: opposition, resignation or approval. Results were expressed as median

Abbreviations: DRNO, do-not-resuscitate order; GFRUP, Groupe Francophone de Réanimation et Urgence Pédiatriques (French-speaking group of paediatric intensive and emergency care); PICU, paediatric intensive care unit; POPC, paediatric overall performance category; PRISM, paediatric risk of mortality

Table 1 Comparison of ethical question-raising and non-question-raising children

	Non-question-raising children median (range)	Question-raising children median (range)	p Value (Fisher's test)
All children	n = 912	n = 55	
Age (months)	60 (1–565)	24 (3–479)	0.005
PRISM score	4 (0–52)	14 (1–52)	<0.001
POPC at admission	1 (1–5)	2 (1–5)	0.019
POPC at discharge	1 (1–6)	6 (3–6)	<0.001
Survivors	n = 878	n = 21	
Age (months)	59 (1–564)	17 (4–431)	0.002
PRISM score	4 (0–41)	10 (1–35)	<0.001
POPC at admission	1 (1–4)	1 (1–4)	0.933
POPC at discharge	1 (1–5)	4 (1–6)	<0.001
Deceased children	n = 34	n = 34	
Age (months)	55 (2–496)	41 (1–37)	0.378
PRISM score[12]	31 (0–52)	17 (0–52)	<0.001
POPC at admission[13]	1 (1–5)	3 (1–5)	0.047

POPC, paediatric overall performance category; PRISM, paediatric risk of mortality.

values, with ranges in parentheses. Fisher's exact test and Wilcoxon's signed rank test were used for qualitative and quantitative comparisons, respectively, and Spearman's test was used for correlations. p Value <0.05 was considered to be significant.

RESULTS

Between September 2002 and August 2004, 967 children were admitted (7877 days of stay), and 68 (7%) died. Median (range) age was 60 (1–565) months, PRISM score was 4 (0–52) and length of stay was 3 (1–575) days. Discussion on limitation of treatments was considered to be necessary in 55 (5.7%) children, with a median delay of 2 (0–173) days after admission. Length of stay of the question-raising children was 14 (1–178) days; prevalence of ethical questioning was 8.4/100 PICU days of stay.

Characteristics of question-raising children

The 55 question-raising children were significantly younger than the others, had higher PRISM and POPC scores at admission and a higher POPC score at discharge (table 1). Among them, 34 (61.8%) died, and represented 50% of all deaths. The 21 question-raising children who survived were younger and had higher PRISM and POPC scores at discharge than the 878 non-question-raising survivors. The POPC score at admission was not different. Among the 55 question-raising children, 25 (45.5%) had chronic disease before admission. Main system failures at admission were neurological (49%), respiratory (27%), cardiovascular (22%) and digestive (2%). System failures leading to questioning were neurological (83%), cardiovascular (9%) and respiratory (7%).

Decision-making procedure

The decision-making procedure was interrupted without a formal treatment decision for 24 of the 55 question-raising children. Decisions for 31 children were made: 12 do-not-resuscitate orders (DNROs), 4 withholding treatments, 14 withdrawing treatments and 1 continuing treatments. In all, 21 (31% of total deaths) children died after a limitation decision (fig 1). Age, PRISM and POPC scores at admission for the 11 children for whom the decision-making procedure was interrupted because of clinical improvement were not different from data of those for whom the procedure was completed.

In the population for whom the procedure was completed, the median delay for initiating the process was two days after admission. The median delay for obtaining opinions of either of the parents after inclusion was 3 days for the mothers and 4 days for the fathers (not significant). The first special decision-making meeting was planned 6 days after inclusion, held on the seventh day after inclusion; parents were informed of the decision on the same day. We found a positive correlation between the delay of expression of parents' opinions and the date of the first special decision-making meeting ($p = 0.008$; table 2).

Period before decision

As recommended in the guidelines, a senior expert was asked to give an opinion on prognosis in 25 children, including the 24 for whom the procedure was completed.

During the study, 180 preliminary family conferences were held to discuss the possible limitation of treatments, which represented 5131 min of medical time. In the population in whom the procedure was completed, there was a median of four family conferences and the total duration was 110 min (table 2). A nurse was present during 31 family conferences, including 22 for children for whom the procedure was completed. The referring resident was present during 42 family conferences, including 25 for children for whom the procedure was completed.

Table 3 gives the details of wishes expressed by 37 mothers, including 23 of the children for whom the procedure was completed, and by 33 fathers, including 18 of the children for whom the procedure was completed.

Special decision-making meetings

In all, 32 special decision-making meetings were organised for 24 children: one for 16 patients, two for 7 patients and three for 1 patient. The median (range) duration was 30 (30–110) min and the number of doctors and nursing staff members was 6 (3–12) and 2 (0–3), respectively. Nurses had worked for 4 (0–30) days at the patient's bed-side. Three special decision-making meetings were organised without any nursing staff member and nine were organised with a nurse who was at the patient's bed-side for the first time. The PICU chief (or his representative) was present at all special decision-making meetings. Parents were informed that there would be a special decision-making meeting in 14 cases, they knew the date in 1 case and they were not formally informed in 17 cases.

During the 24 first special decision-making meetings, there were 2 decisions to continue all treatments, 9 DNROs and 12 decisions to limit treatments. During the seven second special decision-making meetings, one decision to continue treatments was changed into a DNRO, one DNRO was confirmed and five decisions to continue treatments were changed into decisions to

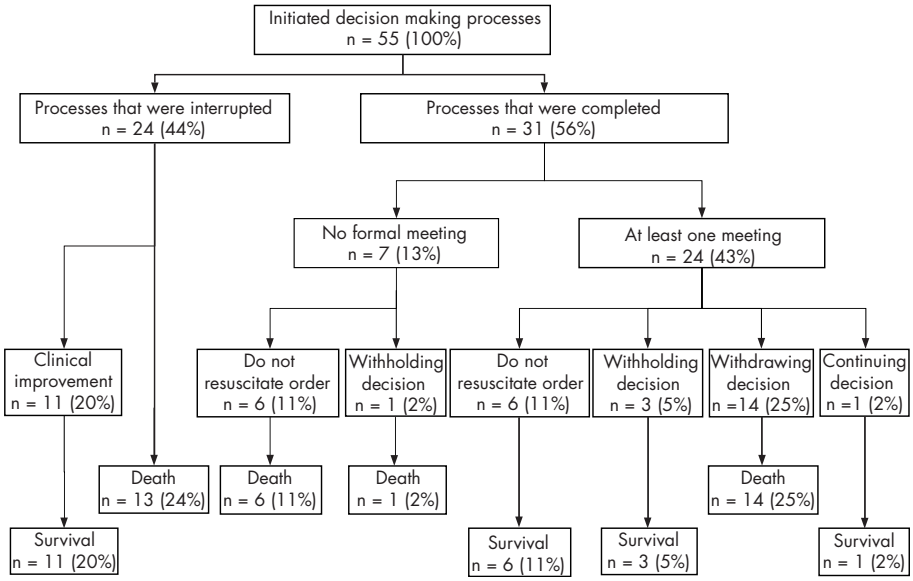

Figure 1 Summary of the decision-making processes.

withhold or withdraw the treatments. During the single third special decision-making meeting, the decision of withholding treatments was changed to withdrawing (fig 1).

Decisions were made without a special decision-making meeting for seven children, all of whom died (six received DNROs and one received a decision to withhold a liver transplantation). These children were older (92 *v* 4 months; $p = 0.012$) and had a higher PRISM score (29 *v* 11; $p = 0.009$) than those for whom a special decision-making meeting was organised.

Among the children for whom the procedure was completed, six decisions were made whereas one of the parents had not formally expressed any wish during the family conferences and two voiced their opposition to the limitation of treatments. In this group, there was one decision to continue treatment according to parents' wishes, four DNROs and three decisions to withhold treatment.

Presenting and implementing decisions

The decision was presented to parents, during a 20 (10–60) min family conference, for 22 of the 24 children for whom a special decision-making meeting was organised, and in one of the seven emergency situations. The decision was approved by at least one of the parents in 18 cases and parents were resigned in five cases. In six situations in which a decision was made without a special decision-making meeting, poor prognosis and the futility of treatment were presented during a single family conference. Reactions were not formally expressed or recorded.

Delay in implementing the decision was 0.5 (0–69) days. Both the nurse and the doctor were present at the bed-side during the implementation of the decision in the 14 cases in which life-sustaining treatments were withdrawn. The option of being present was offered to the parents for 13 of the 14 children and the parents of six children were present.

Figure 1 shows outcomes in children according to decision. All the seven children for whom a DNRO was given at a special meeting survived. Among the four children for whom a withholding decision was made at a special meeting, three survived and one died. All the 14 children for whom a decision to withdraw treatments was made at a special meeting died. All the seven children for whom a limitation decision was made without a formal meeting died. Of the nine children who

Table 2 Dates, delay and time utilisation for decision-making procedures

	Entire question-raising population (n = 55)	Group in which procedure was interrupted (n = 24)	Group in which procedure was completed (n = 31)	Comparison between the groups p value (Fisher's test)
Delay of ethical questioning (days after admission)	2 (0–173)	1 (0–14)	2 (0–173)	0.834
Number of preliminary family conferences	3 (0–14)	2 (0–6)	4 (0–14)	0.005
Use of medical time by preliminary family conferences (min)	90 (0–490)	77 (0–180)	110 (0–490)	0.068
Date of fathers' opinion record (days after inclusion)	2 (−1–70)	1 (0–3)	4 (−1–70)	p<0.001
Date of mothers' opinion record (days after inclusion)	2 (−1–70)	1 (0–3)	3 (−1–70)	<0.001
Date of first decision meeting (days after inclusion)	na	na	7 (0–69)	na
Number of special decision meetings	na	na	1 (0–3)	na
Use of total medical time for decision-making (min)		na	320 (20–950)	na
Date of presentation to parents (days after inclusion)	na	na	7 (0–69)	na
Use of time to present the decision to parents (min)	na	na	20 (0–60)	na
Date of decision implementation (days after inclusion)	na	na	7.5 (0–69)	na
Time between decision implementation and discharge or death			1 (0–135)	
Length of stay (days)	12 (1–178)	7.5 (1–42)	24 (2–178)	<0.001

na, not applicable.

Table 3 Wishes of parents before the decisions and their reactions after the presentation

	Group in which procedures were interrupted (n = 24)		Group in which decision was made without special decision-making meeting (n = 7)		Group in which a special decision-making meeting was organised (n = 24)	
	Fathers	Mothers	Fathers	Mothers	Fathers	Mothers
Parents' wishes						
Limitation	9	10	1	1	18	21
Maximal treatments	5	3	0	0	0	2
Not expressed	9	11	6	6	6	1
Parents' reaction						
Approval	na	na	1	1	16	17
Resignation	na	na	0	0	5	5
Opposition	na	na	0	0	0	0
Not formally announced	na	na	6*	6*	3†	1†

na, not applicable.
*In this group (except in one case), poor prognosis and futility of treatments were simultaneously presented, during a single family conference, because of an emergency situation.
†Because of the absence of one of the parents at the family conference.

survived despite the DNRO, eight were referred to the paediatric neurology department with a severe encephalopathy, and one returned home for palliative care. The POPC score for these patients was 4 (3–5) at discharge. The POPC score of the 11 patients for whom the procedure was interrupted because of clinical improvement was 4 (1–4) at discharge.

DISCUSSION

In our study, the incidence of questioning the appropriateness of treatment was 5% of admitted children, representing >8% of PICU days. The decision-making procedure was interrupted for 44% of children and completed in 56%. In most cases where the recommendations were applied, the main difficulties encountered were finding an appropriate time for a special decision-making meeting and engaging the nursing staff in the procedure.

As our patients were included before the questioning began, our study, when compared with previous ones recording modes of death,[3–5] provides original data. The incidence and prevalence of ethical questioning were both high, reflecting a high level of routine questioning as encouraged by GFRUPs guidelines. The question-raising children were younger, and had worse severity and performance scores at admission than the others, pointing to previous quality of life and severity of illness as questioning factors. Survivors in the question-raising population had a worse performance score at discharge than other survivors, which points to the risk of disability as another questioning factor. Children from the question-raising population who died had less severe PRISM scores than other children who died, pointing out the role of questioning (and probably the role of the decision) in mortality. The 11 children for whom the procedure was stopped without a formal decision because of clinical improvement indicated the problem of the medical conditions for initiating the procedure. Was the GFRUPs procedure fair for these 11 children who survived with severe neurological sequelae? Was their situation fairly judged to prevent a disability that could not be accepted by their family? Given that they eluded the complete procedure, these questions remain unanswered. Definitions of ethical criteria—namely, about neurological status and prognosis— that should systematically require the continuation of the process until a formal decision is made should be the next step in developing the guidelines.

Our study also provides data about the feasibility of the procedure. Among the 31 children for whom the procedure was completed, the GFRUP's main recommendations were applicable in most cases—namely, early ethical questioning, the recording of parents' wishes, formal decision-making meetings and the formal presentation of the decision to parents. The seven bedside decisions did not contradict GFRUP's guidelines. As these children had a higher PRISM score, we can postulate that these decisions actually corresponded to emergency situations, in which planning a special meeting would not be realistic.

The main difficulties in implementing the guidelines were anticipating the correct date for the meeting (mostly scheduled for the next day) and engaging nurses in the procedure. Procedural elements that were proposed by the GFRUP are strongly inspired by Habermas' philosophical theory about the ethics of discussion.[14] Authentic debate, which is proposed for resolving ethical conflicts, requires that all care givers are used as decision-making agents and thus that nurses take part in the procedure. In our study, 10 special decision-making meetings were organised without a nurse, or with a nurse who was in charge of the patient for the first time. In our study, nurses were present at <20% of family conferences. This lack of participation contrasted with their constant presence at the patient's bed-side at the time of implementation of the decision, corresponding with a more traditional role. In our PICU, conditions for nurses' participation have been previously formally discussed to make it compatible with French legal texts that define their role (literally in French ''own role of nurses'').[15] The fact that doctors have previously analysed medical conditions before considering the possible limitation of treatment was recognised as protecting nurses from transgressing their legal role. The lack of nurses' participation, even partly explained by the difficulties in scheduling family conferences and decision-making meetings, suggested that their level of involvement in the procedure remained lower than ideally conceptualised in the authentic debate philosophical model.

Even if formal US guidelines have been available since 1994, whether practices in US PICUs follow the guidelines or not remains unknown.[6 16] However, data obtained from a recent European study[5] pointed out interesting trends that may help to assess the effect of implementation of the guidelines in our PICU. This study[5] prospectively compared forgoing life-sustaining treatments in 27 PICUs from south European countries (mainly French ICUs) versus 12 PICUs from north European countries. The authors noticed that the decisions were more often documented in north European PICUS (100% *v* 48%; p = 0.001); that parents' opinions were more often recorded (62% *v* 42%; p = 0.06); and that parents were more often informed of the decision (95% *v* 68%; p = 0.01). They attributed

Box 1 The five steps of the procedure proposed by the French-speaking group of intensive care doctors[11]

1. Questioning about the appropriateness of the treatments

- Questioning about the appropriateness of the treatments is part of the role of all categories of care givers. Routinely, it consists of choosing the treatments that give the greatest proportion of medical benefits in comparison to harms.
- When the questioning is expressed by the children or their parents, care givers must inform the doctors, so that it can be taken into account.
- Doctors must give true information to both parents and paramedical staff, and must encourage and arrange for team questioning during routine staff meetings.

2. Organising a special decision-making meeting

- Medical reasoning implicitly assumes that the best interests of the child are ensured by medical knowledge. When medical reasoning alone is not able to respond to questioning, doctors must organise a special decision-making meeting to consider factors other than medical.
- This meeting must be anticipated, scheduled and announced to permit all care givers in charge of the child to be present.

3. Explanation of the decision

- A decision must be made at a special decision-making meeting that must be exclusively devoted to the problem.
- A medical analysis of the situation must be the first step undertaken at the special meeting.
- After the medical analysis, it may seem that the problem was falsely deemed ethical and that medical reasoning is able to respond to the questioning. It may also seem that some medical elements were lacking and that the meeting must be rescheduled.
- If the ethical conflict is validated, non-medical factors must be considered in decision making. It includes human (acceptability of the treatments by the children or their parents, quality of life, etc) and sociocultural (ethical and deontological principles, risks of litigation, etc) factors.
- An authentic debate is proposed for resolving ethical conflicts. All treatment options, from maximal treatment to palliative care, must be considered and their consequences must be appreciated.
- Principles of ethics of communication must be respected during the discussion, all arguments must be considered and opportunities for speaking should be fairly managed.

4. Decision making

- As debating requires that all care givers are used as decision-making agents, collegiality is a necessary condition for decision making, but it does not ensure the quality of the decision by itself.
- Collegiality must be considered to be a help for the doctor making the decision, but it must not shift the weight of the decision onto paramedical staff.
- If there is a consensus for the decision to limit life-supporting treatments, a modality must be chosen. Decisions could include a do-not-resuscitate order in case of cardiac arrest, withholding new treatments or withdrawing current treatments.

5. Implementing the decision

- A decision must be announced to the child, parents and paramedical staff.
- Time must be given to parents to accept or contest the decision, and they must be asked whether they want to be present at the bed-side when the decision is implemented.

these differences to the use of guidelines in north European countries.[6–8] Our data were in accordance with those obtained from north European countries, proving the positive role of guidelines in formalising and documenting the decisions. Also, the interval between the decision and its application was less than 1 day—lower than that reported in south European countries. This result supports the hypothesis that formalising the procedure leads to the better preparation of parents for a decision.[17] In our study, the proportion of deaths after a decision to forgo life-sustaining treatments was 30%, which was close to that reported among south European countries, and lower than that reported among north European countries (47%).[5] It was also comparable to the proportion reported by two recent studies from countries with a predominant Latin culture.[18 19] It remains lower than the proportion reported by Burns *et al*[20] (53%) in a recent prospective study from the USA. In our study, as in Devictor's[17] study of a south European country group, causes of ethical questioning were largely dominated by neurological failure, whereas respiratory failure dominated the cause in north European countries. This remaining congruence with data reported from other Latin countries leads us to hypothesise that the implementation of a formal procedure does not change the incidence of ethical questioning or the ethical principles on which the resolution of ethical conflicts are based.

In a 4-month study carried out in 33 French PICUs, 80% of decisions were made at a decision-making meeting, a nurse was present in 50% of cases and parents in 6%.[4] Parents' wishes were known in 72% of cases, 10% of the parents knew that a decision-making meeting would be organised and decisions were presented to parents in <19% of cases.[4] The paper was accompanied by an editorial entitled ''Parents should not be excluded from decisions to forgo life-sustaining treatments''.[21] In our study, data on parents' wishes before the decision and their reactions after it was presented (table 3) showed that doctors did not search for informed consent, but for the absence of opposition. The guidelines recommend giving parents the choice of their level of participation in the procedure, which shows a dual ethical purpose of recording their wishes without shifting the weight of decision on to them. Conceivably, the absence of informed consent may classify these decisions as a form of malpractice, but GFRUP's guidelines claimed that the right of parents to full autonomy does not exclude their right not to take part in decision making. The positive correlation between the dates of the expression of parents' wishes and dates of decision indicated that parents' autonomy was taken into account. It seems that GFRUP's guidelines remain more doctor centred (paternalistic?) than policy expectations would suggest for the US, but in a recent qualitative study, Carnevale *et al*[22] showed that French parents agreed that life-support decisions should be made by doctors. Recently, the French law about patients' rights at end of life ratified that the decision must be made by the doctor who is in charge of the patient, after recording parents' wishes and asking for the opinion of a colleague.[23 24]

Our study had some limitations. Firstly, it consisted of a single PICU participating in the development of the guidelines. Our study must be considered as a pilot study: a 20-centre prospective study is about to start in few months. Secondly, limitation is due to its self-monitoring design. To avoid the biases of declarative studies, we took care to record only objective data, such as facts, dates and actors.[25] Because of the absence of an independent investigator, decision motivations and discrepancies between perception by doctors and nursing staff could not be studied. Nevertheless, quantitative studies remain useful for evaluating the implementation and feasibility of guidelines, for inducing local reflection on practices and for

orienting qualitative studies. We chose to detail all the types of decisions separately (fig 1) instead of pooling to carry out statistical analysis, because it is more illustrative of the variety of situations and more representative of their complexity. Practices could be optimally surveyed in a permanent PICU network, with a common database. This database could be anonymously fed by members, who would receive their individual position compared with the summary of median practices of the entire group.

CONCLUSION

GFRUP's guidelines seem to be fully applicable in most cases and seem to have a positive effect on better formalising procedures, and better informing parents and preparing them for the decision, but probably not modifying the ethical principles on which the decisions are based. Main difficulties identified were anticipating the correct date for decision-making meetings and including the nursing staff in the procedure. Children for whom the procedure was interrupted without a formal decision raised the question: was the decision fair for them? This pointed out the need for medical criteria, which should systematically impose the continuation of the decision-making process towards a formal decision to ensure a fair decision in each case.

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